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Relationship Between Family Involvement in Nursing Home Care Planning and Advance Directive Use

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The views and opinions expressed in this presentation are those of the presenter and do not necessarily reflect the official policy or position of the funder.

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Background

- 20% of nursing home residents with advanced disease experience multiple hospitalizations in the last 90 days of life[1]
- Documenting preferences for less aggressive end of life care, in the form of an advance directive, is associated with fewer hospital transfers and increased hospice use at the end-of-life[2,3]
- 96% of nursing home advance directives are established by a family caregiver or other proxy, usually after burdensome care is received[4]
- Family caregivers report a lack of necessary information to make treatment decisions,[5,6] and inadequate communication with providers[7]
- When prognosis and treatment options are discussed with a provider, 93% of proxies prefer comfort care for their loved one[8]

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Background

- Nursing homes are required to conduct comprehensive assessments of residents at admission, with a change in status, and once per quarter
- Nursing home residents and their representatives are to be included "to the extent practicable"
- Only 8% of residents without cognitive impairment and 26% of residents with severe cognitive impairment had any family involvement in a quarterly or annual assessment during 2016.[9]
- Family members of long-stay nursing home residents may be more likely to be involved early in a nursing home stay
- Using admission care planning meetings to discuss and document end of life care preferences may improve outcomes for residents who are likely to spend the rest of their lives in the nursing homes

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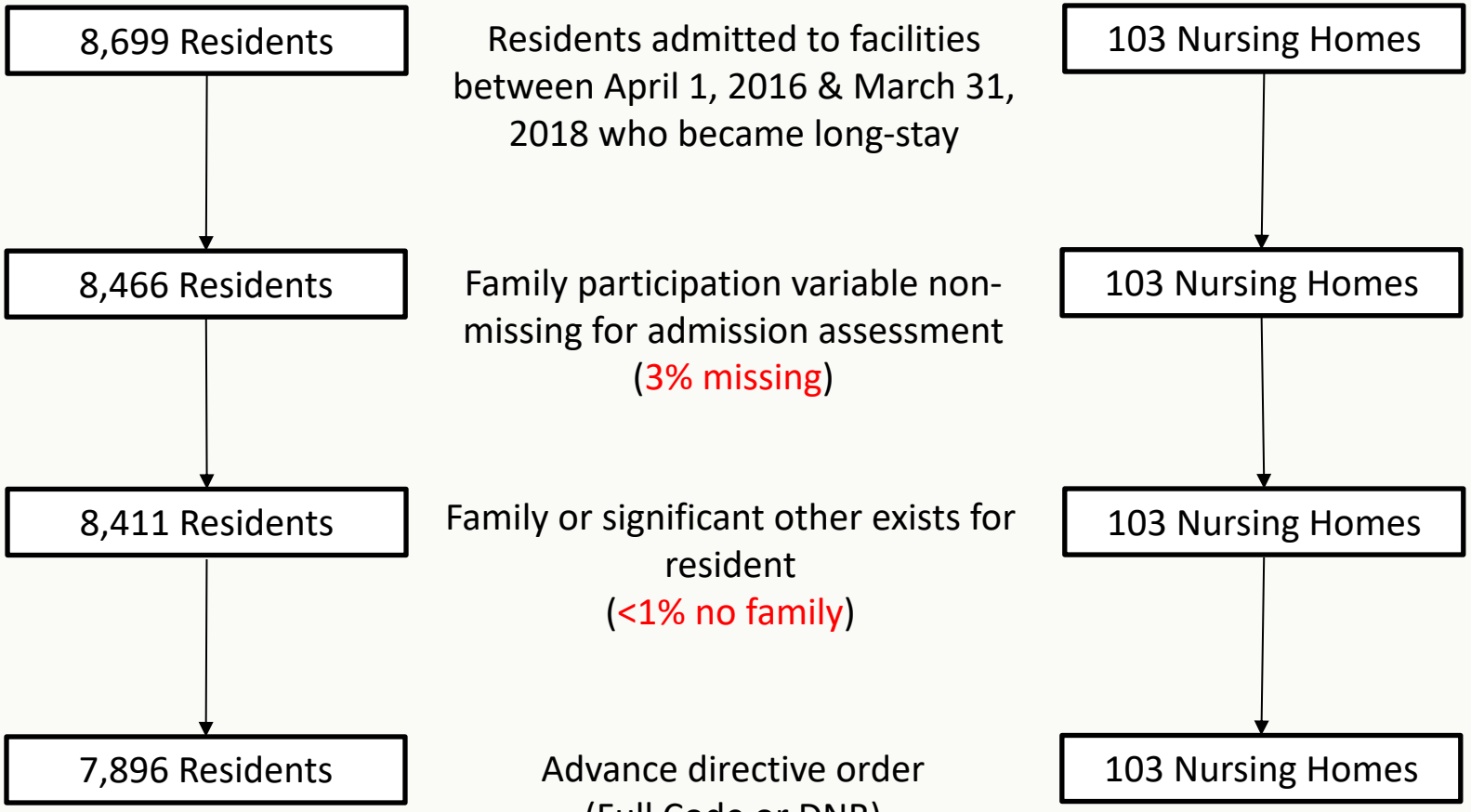
Aim

Determine whether nursing home residents who have a family member involved in a care planning meeting at admission are more likely to have a do-not-resuscitate (DNR) order when they become long-stay, after controlling for cognitive and physical function at baseline.

Methods

- Residents who were admitted to a participating nursing home between April 1, 2016 and March 31, 2018 and subsequently became long-stay (had a quarterly assessment in the same nursing home within 4 months of entry into facility)
- Family participation in comprehensive admission assessment based on Minimum Data Set (MDS), Section Q, Item Q0100B
  - Family or significant other participated in assessment
    - (0) No
    - (1) Yes
    - (9) No family or significant other
- Full code or Do-Not-Resuscitate status based on Electronic Health Record (EHR) advance directive physician order data
- Dementia diagnoses (MDS-based, checkbox or ICD), Cognitive Function Scale
- Estimate marginal adjusted predicted probability of DNR at 100 days using probit model with random intercept for nursing homes

Results



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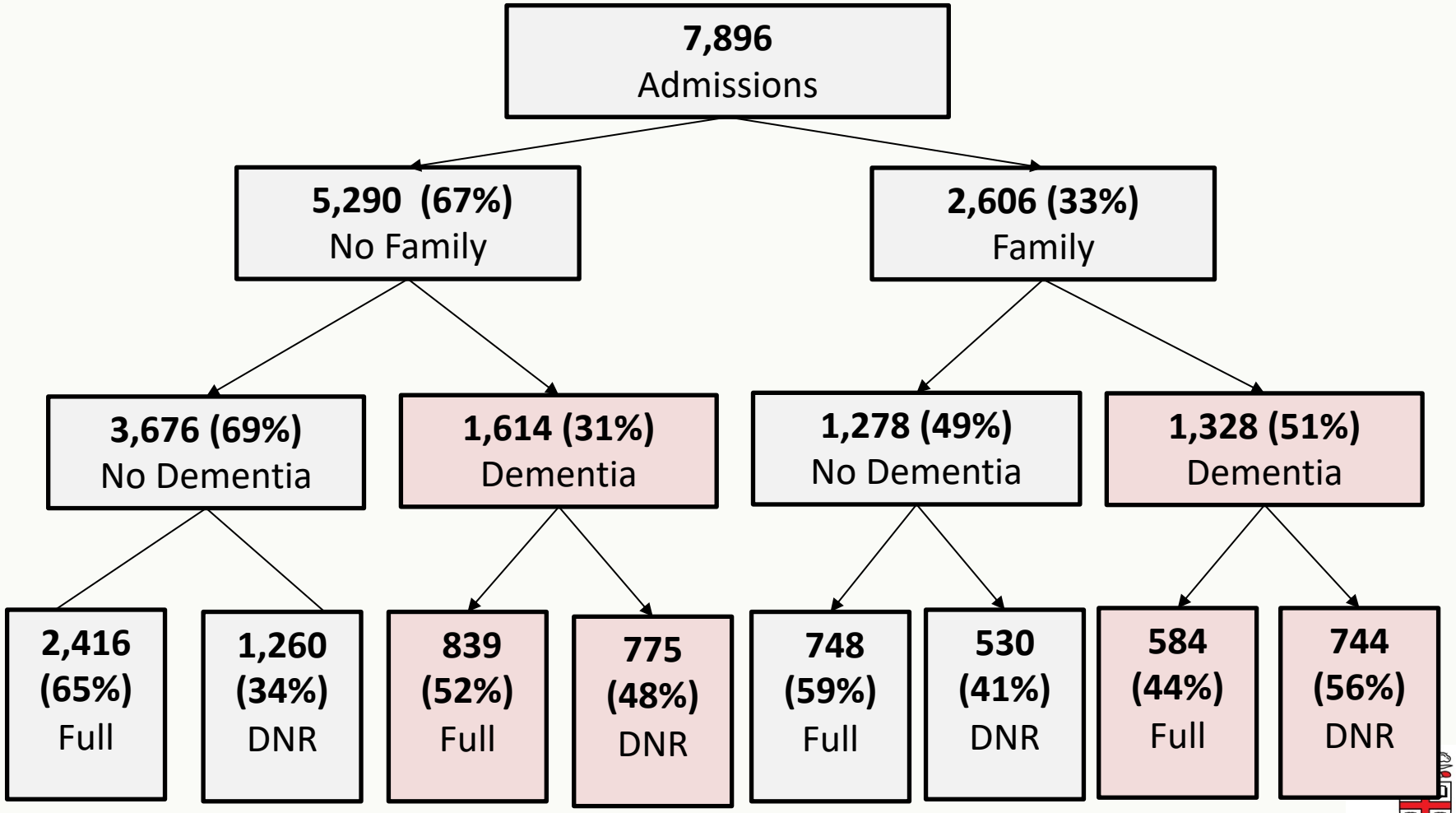
Results

	No Family (n= 5,290)	Family (n= 2,606)
Age, mean ± SD	74.9 ± 13.8	78.7 ± 12.3
Male, No. (%)	2,167 (41%)	2,167 (40%)
Married, No. (%)	1,055 (20%)	761 (29%)
Race, No. (%)		
White	4,491 (85%)	2,179 (83%)
Black	423 (8%)	235 (9%)
Other	106 (2%)	130 (5%)
No Race Specified	270 (5%)	62 (3%)
Ethnicity, No. (%)		
Hispanic or Latino	157 (3%)	86 (3%)
Moderate or severe dementia, No. (%)	1,198 (23%)	1,343 (52%)
ADL dependencies, mean ± SD	5.1 ± 2.8	5.7 ± 2.7

Other variables in full model: CHESS score, dementia diagnosis, schizophrenia, cancer, end-stage renal disease, stroke, diabetes, hypertension, intellectual disability, needs interpreter, antipsychotics, agitated behaviors, antidepressant, antianxiety, staff or resident reported pain, hospitalizations (count)

Results



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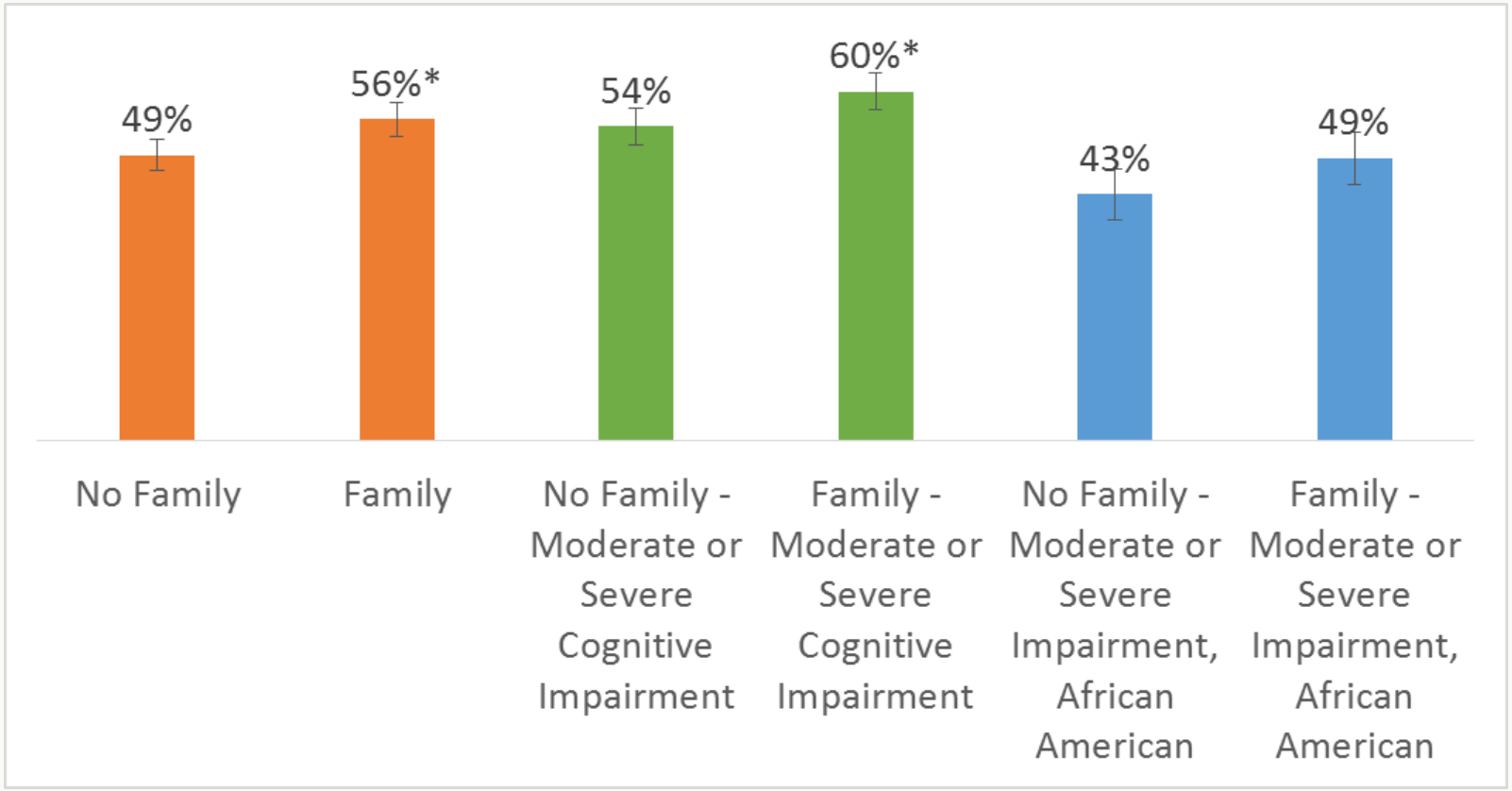
Results –Probability of DNR at 100 Days



Model adjusted for age, sex, marital status, race / ethnicity, ADL dependencies, degree of cognitive impairment, CHESS score, dementia diagnosis, schizophrenia, cancer, end-stage renal disease, stroke, diabetes, hypertension, intellectual disability, needs interpreter, antipsychotics, agitated behaviors, antidepressant, antianxiety, staff or resident reported pain, hospitalizations (count)

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Limitations

- Potential for residual, unobserved severity
- Lack of understanding of how Section Q participation variable is completed by MDS nurse
  - lack of understanding of what family participation in care assessment really means
- Lack of understanding of mechanisms underlying family participation and advance care planning
  - we don't know which provider(s) communicated with the family member or what they discussed
- No information on relationship type (e.g., spouse / partner, child), or other family visitation

Discussion

- Family members, who are primarily responsible for making advance directive decisions, are more likely to be involved early in a nursing home stay
- Family involvement in care planning at admission may result in earlier documentation of advance directives for nursing home residents with advance dementia and other advanced disease
- Release of MDS, Section Q data would help researchers identify ideal intervention windows to improve provider-family communication and subsequent proxy decision-making
- Nursing home EHRs may be a good source of advance directive data

Questions / Contact Information

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